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The Honorable Secretary Shinseki
Department of Veterans Affairs
810 Vermont Ave. NW
Washington DC 20420

Dear Mr. Secretary:

As Chair of the VA Genomic Medicine Program Advisory Committee (GMPAC), it is my privilege to guide the activities of this vitally important panel of experts and to provide you a brief summary of the discussions at the eighth meeting held on April 27, 2009 in Washington DC, as well as my recommendations for the VA.

1. The agenda included program updates on ongoing and planned projects, a discussion of policy-related topics including a recent report on patient privacy from the Institute of Medicine and on the oversight of genetic testing by a representative from the Centers for Medicare and Medicaid Services, and finally presentations and discussions by scientific experts from within and outside the VA on the current knowledge in the fields of genetics of diabetes and breast cancer. The presentations were followed by stimulating discussions among the members of GMPAC.
2. The committee commended the VA on the progress made on various fronts, including: (1) an initial survey of veterans assessing their attitudes, support and concerns; (2) laying the foundations for genomics research infrastructure through core research facilities, databases and informatics; (3) funding and planning large-scale genomic studies in areas of relevance to veterans such as amyotrophic lateral sclerosis (ALS), post-traumatic stress disorder (PTSD) and severe mental illnesses; and (4) funding a prototypic web-based educational tool on the genetics of colorectal cancer for health professionals within and outside the VA. **The committee recommends that the VA continue to develop these resources to build the program and at the same time develop policies that ensure the safety and privacy of veterans.**
3. Two planned projects presented at the recent meeting were of great interest to the committee. The first related to a follow-up survey of veterans. An initial

survey conducted for the VA by the Genetics and Public Policy Center (GPPC) at Johns Hopkins University was recently published in the journal *Genetics in Medicine*, and showed that 83% of veterans supported the establishment of a genomic medicine program and 71% were willing to participate. The proposed follow-up survey would assess whether veterans would support the use of residual clinical samples for genomics research and how they would like to provide consent for participating in these studies. This follow-up is critical since the use of residual clinical samples can greatly enhance the ability to enroll large numbers of veterans into the program in a shorter time frame and accelerate scientific research that could be translated into clinical care. It will be important to find out if veterans support this approach. **The committee recommends that the VA move ahead with the follow-up survey expeditiously.**

The second project is related to the recruitment of veterans to participate in the genomic medicine program by donating a sample such as blood or saliva to be banked at a VA central biorepository. Genetic data obtained from the sample will be stored in a central research database. Information obtained from a health survey conducted at the time of enrollment as well as medical information extracted from the electronic health record would also be stored at the research database. All data will be coded so that the participating veterans cannot be directly identified. Results from a pilot study comparing different recruitment strategies were presented at the meeting. **The committee considers this to be a highly significant project, unparalleled in any other healthcare or research organization. The VA is uniquely positioned to set up such a database with the potential for enrolling several hundreds of thousands of Veterans and being able to address scientific questions that would otherwise not be possible. This in turn could lead to genetic and genomic discoveries that would enhance the healthcare of Veterans. The committee recommends that the VA complete the pilot and pursue strategies to determine optimal enrollment in the genomic medicine program.**

4. Lastly, I endorse the recommendations made by the GMPAC Working Groups on Hereditary Non-polyposis Colon Cancer (HNPCC) and Multiple Endocrine, Neoplasia and encourage the VA to consider the same. These recommendations are in a separate attachment.

Please let me know if you would like any additional input from the GMPAC on these matters. All of us on the committee consider this effort of tremendous importance, both to the veteran population and indeed to the health care of all U.S. citizens, since the VA system represents such an ideal, dedicated setting for the incorporation of the newest advances in genomic medicine.

Thank you for your consideration of our recommendations and for your continued support of this pioneering program.

Sincerely,

A handwritten signature in blue ink, appearing to read "Wayne W. Grody". The signature is fluid and cursive, with a prominent "W" and "G".

Wayne W. Grody, M.D., Ph.D.

Professor

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